

The Picture of Health?

In the first article of a three part series on **CANCER**, **JO SPENCE**, who is an educational photographer, describes her struggle for health as a cancer patient, and how she uses photography and alternative medicine to bring about necessary changes in her life.

JO SPENCE & ROSY MARTIN



A phototherapy session on powerlessness.

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When I first realized I had breast cancer ... I went home and waited to die

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▷ Three years ago I was diagnosed as having breast cancer. Like so many women before me I submitted myself to the medical machine, going along with the treatment as far as to have a lumpectomy performed on me. The feelings generated in the circumstances surrounding this were so totally negative that I felt, come what may, that I had to get off the production line set up by the medical orthodoxy. So I did. I wanted to write here a 'happy ever after' story, but unfortunately this is not it. Nonetheless I feel it is worth writing about what has happened in between then and now.

I am not better, in spite of beginning to take responsibility for my own health, and working out an integrated programme of health care with others. On the other hand, although I still have active cancer, and my general health is not good, I feel more in control of my life than at any other time previously. This has come about because of the questions I have been forced to ask myself about my belief system, my lifestyle and my attitude to my mind and body. As a result I see myself neither as 'heroine' or 'victim', but merely as a person in struggle, changing and adjusting daily, and trying to keep a state of equilibrium which will allow me to function optimally, at the same time as I strive to regain health.

When I first realized I had breast cancer I felt that I had been stricken and marked in some way which left me outside the experience of everybody else. The labelling of the disease was tantamount to having a curse put onto me. I went home and waited to die. Fortunately, friends were unable to accept this passivity on my part and plagued me with literature which seemed to offer other ways through the illness and initially I took myself off to the Bristol Cancer Help Centre. Here I was introduced to a philosophy of patient-centred medicine, whole mind and body therapy, and the idea that we can begin to be involved in trying to have a say over how we become well again, or manage our disease to our own satisfaction.

Apart from the fact that, thirteen years ago, my own mother died of liver cancer six weeks after a mastectomy, (a fact I had completely disavowed, of which I had no real memory, in spite of being present and an accomplice to her euthanasia), I had no knowledge of the disease apart from a few anecdotal horror stories from friends and relatives, and the media coverage of various 'victims' of the disease. In spite of having earned myself a first class honours degree as a mature student, I still had no clue as to how my body worked, or even where my liver was situated.

I wouldn't say that I ever saw myself as an 'ill' person. Yet in retrospect, illnesses of one sort or another have dogged most

of my life - most especially asthma, hayfever, eczema and bronchitis. These don't sound much but were like a long running soap opera, appearing regularly at times of stress, exhaustion, over indulgence, environmental extremes - always being treated by drugging or surgery. At 28 years I developed an ovarian tumour (14 lbs weight at the time of my operation), as a result of the 'side effects' of steroid treatment for asthma. And still I didn't learn. Years later, after two attempts to detoxinate myself through naturopathic medicine (my liver having practically packed up), and each time running out of money to continue with such private treatment, I eventually had breast cancer diagnosed.

The treatment offered for this was mastectomy, and if necessary, a further mastectomy if it developed in the other breast. Nothing more or less. It never occurred to me until I was in hospital waiting for the ward rounds with the results of the needle biopsy, that I had any rights in the matter. That I could just put my clothes on and go home. Refuse their treatment. That is until the incredible insensitivity, lies, evasiveness and uncaringness began. What happened to me is hardly any different from what other women have told me, so it was fairly 'normal' procedure it seems. To me it disgusted me so much that I finally found voice to refuse a mastectomy, after bedside arguments at the last minute with 'my consultant', who finally conceded that I have only the tumour removed, and that we'd take it from there.

Since that time I have not been back, but pursued a path which lead me towards alternative medicine. However, in spite of my care and attention to diet, stress levels and lifestyle, always under the vigilance of either a naturopathic, or (latterly) somebody who practices traditional Chinese medicine, the tumour has grown back on the site of the previous operation and steadfastly refuses to budge. But I feel this is hardly surprising as my body is still trying to throw off the years of toxins held in the tissues, and I am still trying to work through any number of self destructive patterns of eating and behaviour in therapy.

Because I am a practising photographer, having worked within the education sphere for many years, I began to ask myself questions about how disease and health are represented to us. Given that women are expected to be the object of the male gaze, are expected to beautify themselves in order to become loveable, are still fighting for rights over their own bodies which are very fundamental, it seemed to me that the breast itself can be seen as a metaphor for our struggles. The fact that we have to worry about its size and shape as young women, its ability to give

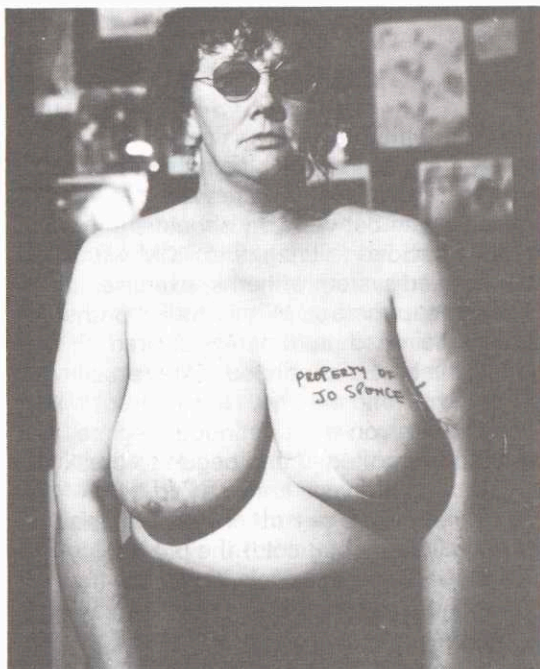
food when we become mothers, and its total dispensability when we are past childbearing age, should be explored through visual representation, as well as within healthcare itself. The two should not be separated out in any way, as our concept of sexuality and our social identity both stem from lived experience and our own imaginary self carried in the mind's eye. Just as the female body is fragmented and colonized by various advertisers in the search for new markets for products, and through pornography is fetishized and offered for male consumption, so the body is similarly fought over by competitors for its medical 'care'. There are no departments of 'whole body' medicine in any hospitals I have ever attended. The concept is quite alien at any institutional level, although individual doctors and nurses are clearly interested in such a type of medicine.

How then do we begin to see and experience ourselves 'holistically' when we have always been dealing with 'body bits' which we perceive as deficient in a variety of ways?

In the system of medicine for which I finally opted (Traditional Chinese Medicine - TCM), the patient is encouraged to begin to take some responsibility for getting and staying well. At the very least this means more work for the patient, and the necessity to make informed decisions; at its best it means a complete change of outlook on the world and the shattering of lifelong habits in relation to food, drugs, exercise, breathing, and the awakening of the knowledge that the body cannot deal forever with a completely unharmonious relationship with one's psychic, spiritual, social, economic living and loving conditions. In plain english, for me, this meant that I learnt to love myself better and get more in touch with my actual needs and feelings so that I could start to try to change things wherever possible.

It is my belief that Traditional Chinese Medicine offers me the best chance of survival as a cancer patient, or at least a better 'quality of life'. It does not pretend to offer me a 'cure', but is a way of managing the illness, putting it at bay, or perhaps slowing it down. It involves long term planning and care, making great changes in my daily routine, does not build up toxins in the body and mobilizes the body's own resources and defence system. There is also continuity in medical care.

With a radical change of diet (details below) my long term depression began to ebb away and my general health improved considerably. I lost four stone in weight, could breathe better, asthma and hay fever virtually vanished and I went through the early winters bronchitis-free. The scar tissue from the operation was rock-hard but within months began to soften.



JO SPENCE & TERRY DENNETT

Jo Spence before going into hospital - 'providing a talisman for myself, to remind me I had rights over my body'.



JO SPENCE & TERRY DENNETT

The breast itself can be seen as a metaphor for our struggles

'The analogy between the war on cancer and the war in Vietnam is more than metaphorical. Since the rise of the cellular hypothesis - that cancer is a mysterious, tumorous condition of localized origin - the medical establishment has sanctioned only three methods of treatment: surgery, radiation, and chemotherapy. On a larger scale these are precisely the three major weapons (search-and-destroy, bombardment and chemical warfare) utilized militarily against social problems (ie political and economic insurrections) in Vietnam and other parts of the Third World.' (Alex Jack. CANCER CONTROL JOURNAL. Vol.5, No 3/4)

However, within ten months on a naturopathic regime my breast began to swell (like mumps) and there was extensive pain between my shoulder blades. I decided to change to TCM with its integrated system of herbs, exercise, diet and acupuncture. Within four months my back pain had more or less cleared, though the breast continued to increase in size and the lump enlarge. Now, after fifteen months on this continuous regime the lump has softened and begun to break down, though it has a long way to go. Every time there is any other kind of crisis in the body (eg a bad cold) the breast tends to harden and remain inactive. Throughout the treatment I have been able to continue to work part time, though my energy levels fluctuate wildly if I do not rest enough. There has been a lot of

acute pain in different parts of the body, coming and going as the liver copes with the detoxination process, the intestine takes on new bacterial fauna, and the body settles into new posture from exercising.

My TCM practitioner is Yana Stajno, whose partner David Lurie prescribed herbs to me on a weekly basis, taking account of my total condition at any point when he prescribes. I see Yana as a traditional female healer, in that she uses her hands, her medical skills and counsels me whilst she is attending me. We have a totally professional relationship yet, within it, we discuss ways in which I treat her as a surrogate mother, but in which she returns that power to me continually. I have experienced love and care from both her and David which is without parallel in my years of continuous medical treatment by general practitioners and hospital personnel. They charge me on a sliding scale at their lowest fee as such medicine is not available on the NHS. Traditional Chinese Medicine is either picked at as a medical commodity (eg acupuncture), or else is sneered at by western cancer specialists, who thereby display an alarming degree of ignorance (and racism), believing that their recently evolved systems of treatment are far superior to thousands of years of cumulative health care within TCM. In China both traditional and orthodox treatments are available for cancer and patients can (in theory at least) have access to either or both systems. The regime for rebalancing my whole body and my psychic life is as follows:

Long term change of diet (to a macro-biotic diet, occasional white meat or liver - which needs to be organic; plenty of fruit and vegetables, some nuts and seeds, fresh sprouted seeds and beans), freshly juiced fruit and vegetables. No sugar, salt, gluten, dairy products, most animal products, no preserved, tinned or processed food at all.)

Daily Qi Gong exercise (routinely part of treatment for cancer in China, which helps circulation, breathing and general energy distribution, as well as strengthening the body)

Twice weekly acupuncture

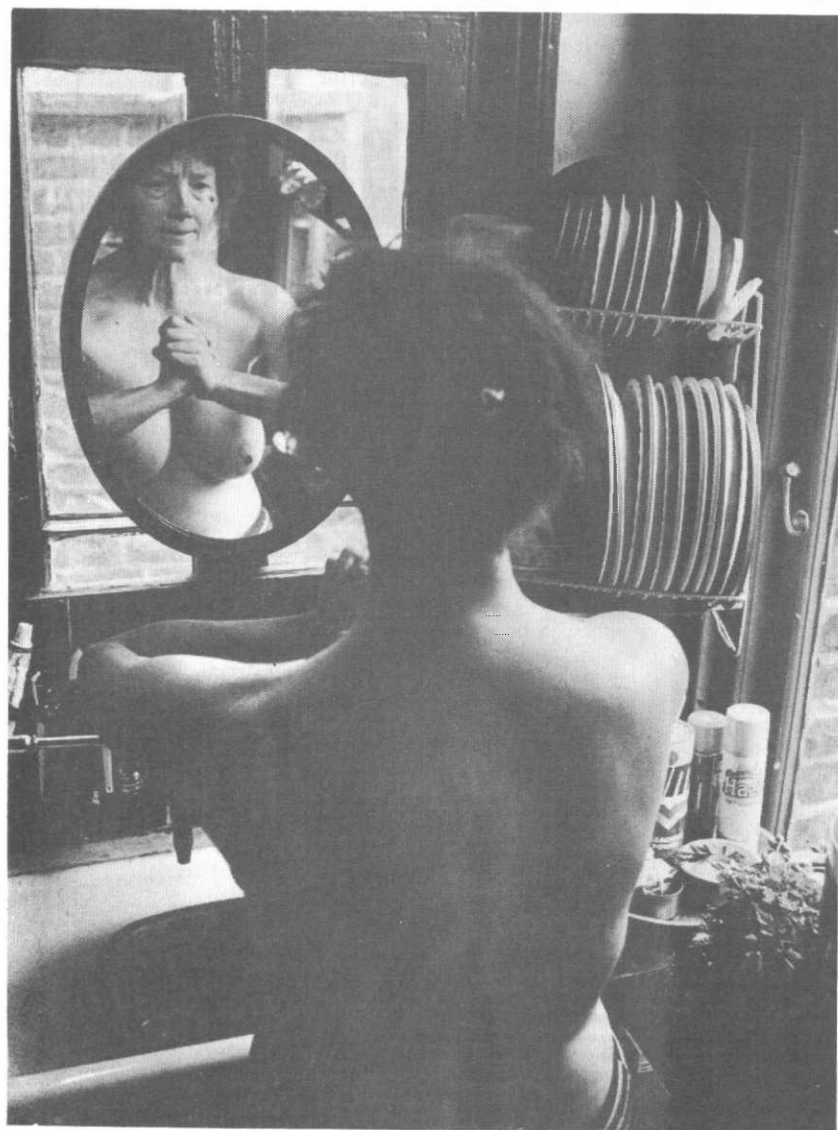
General health care through Chinese medicine

Occasional lymphatic massage

Daily megadoses of Vitamin C and mineral supplements

Herbal intake daily (brewed up from raw dried Chinese herbs in my kitchen

Monitoring of stress levels



MAGGIE MURRAY & JO SPENCE

Daily home exercise as part of an integrated healthcare programme for breast cancer.

A loving relationship and reciprocal counselling sessions with David Robelts my partner in life

Plenty of cuddles and bodily contact with others

I work part-time as a secretary, as well as continuing with my work as an educational photographer (on the proceeds of which I would starve). I receive local government rate and rent support, sometimes draw supplementary benefit and am supported by my partner financially if there is absolute necessity. There have also been intermittent donations from friends towards my health costs for which I have been grateful.

WHY PHOTOGRAPHY HAS BEEN IMPORTANT.

Even whilst I was in hospital I began to try to represent to myself what was happening to me by using my camera. But how to represent *myself to myself*, through my own visual point of view, and how to find out what I needed and to articulate it, and make sure I got it? Ultimately wanting to make this visible to others. And, eventually, how to deal with my feelings about myself, and give them visual form.

During the course of my illness I came to the conclusion that one of the major absences in my own family history and archives was any knowledge of what had happened to other members of my family in terms of mental and physical illnesses.

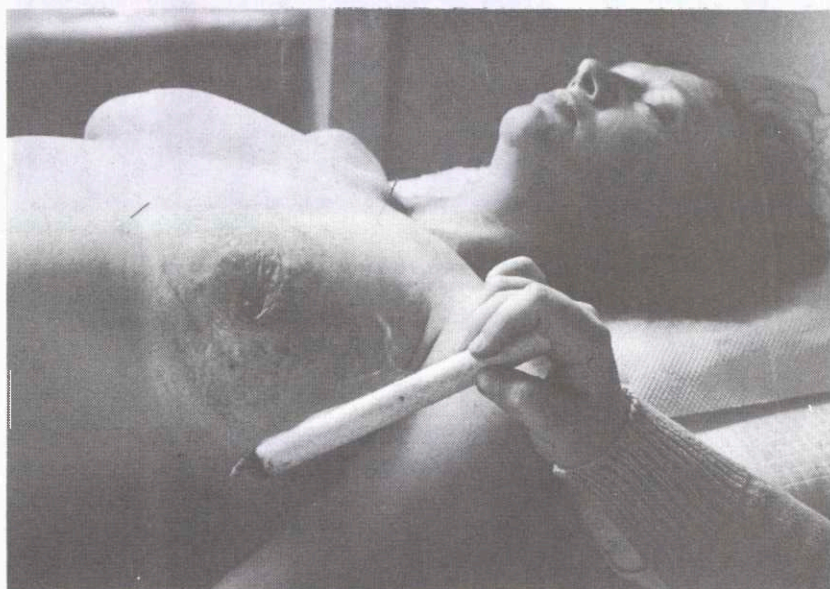
In looking through my family photographs (even though I had already done extensive work on them in *BEYOND THE FAMILY ALBUM*) I now realize that they actually hide any evidence of illness or aging, as photographic conventions encourage us to always show the 'bright side', or to 'smile' for the camera, and the lack of clarity in small images prevents us from seeing any fine detail. I finally made up a health chart of my own life, including banal snapshots of me, as against details of diseases and treatments, which crystallized for me the paucity of family records. This led to my deciding to visually document my own struggle for health, and to try to see how that allied itself to struggles that others are making.

I believe it should be everybody's right to take photographs inside all state institutions. So, on the last two occasions when I went into hospital, I photographed a lot of what happened around me. Using delayed action on my shutter in some instances I was able to include myself in the picture, but I never had the nerve to photograph anything happening to ME directly, least of all my appalling treatment at the hands of consultants, which in any case would have warranted a video camera with sound.

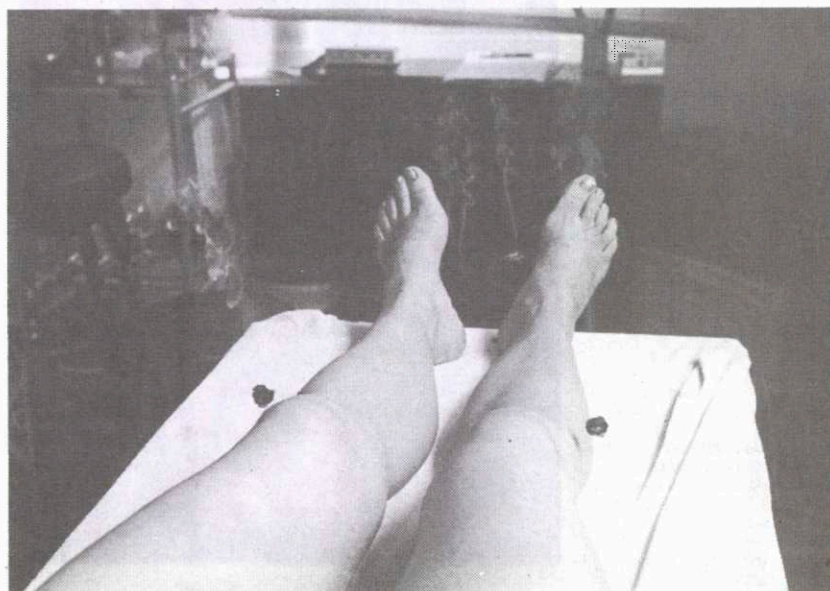
PHOTO THERAPY

I am continually asked 'what is photo therapy'? It means, quite literally, using photography to heal ourselves. As part of my health project I have been working on my stress and anxiety levels, reviewing my life in general and trying to understand the part that psychic life (phantasy/fantasy) plays in my well being, or otherwise. Particularly, I have worked with Rosy Martin, a sister co-counsellor, who shares similar interests in cultural politics with me. Photo therapy should be seen within the broader framework of psychoanalysis and its application to the photography of family life, but should always take account of the

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Moxibustion and Acupuncture treatment for breast cancer (traditional chinese medicine)



Acupuncture, combined with herbal treatment (moxibustion).
'Whole body medicine, or holistic health takes account of the general condition of the patient.'

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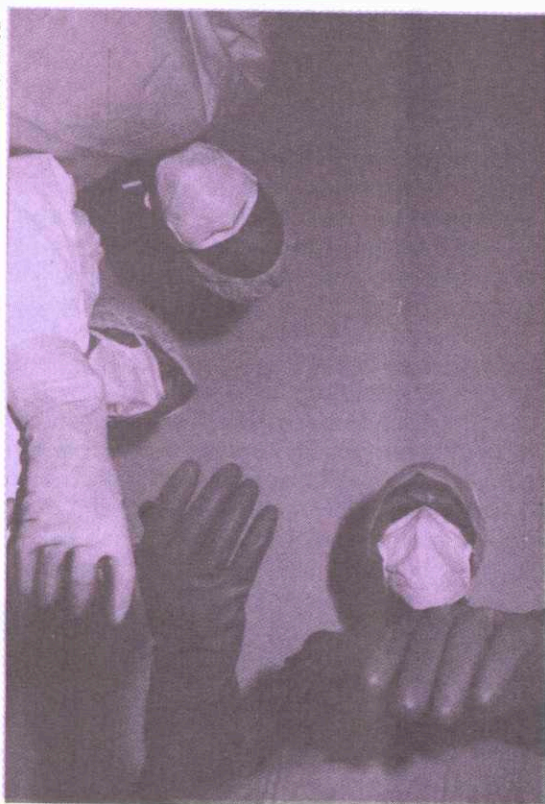
MAGGIE MURRAY (FORMAT)

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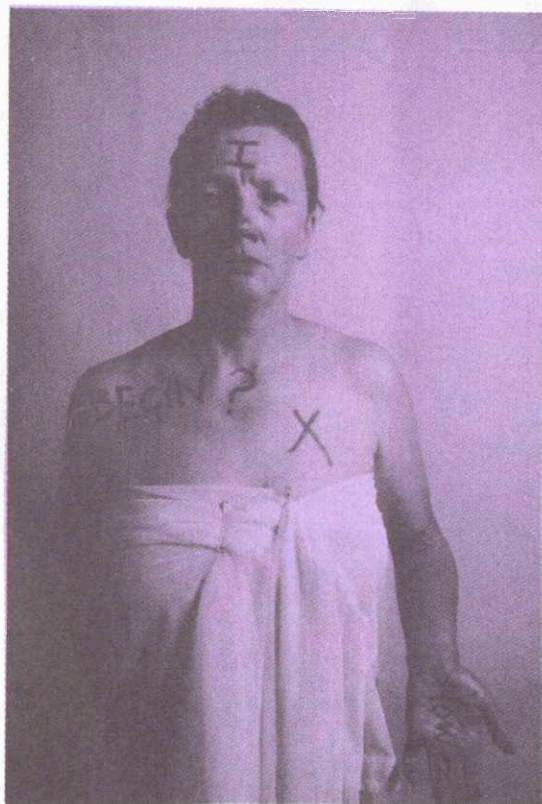
There are no departments of 'whole body' medicine in any hospitals I have ever attended.

JO SPENCE



'In phototherapy, I re-enacted the trauma of my own powerlessness and lack of knowledge about my body.'

JO SPENCE/ROSY MARTIN



'Marked up and ready for amputation, I ask myself new questions during a phototherapy session with Rosy.'

possibility of ACTIVE CHANGE. We drew upon techniques learned together from co-counselling, psychodrama, and a technique called 'reframing'.

Using this technique, Rosy and I began to work together to give ourselves (and each other) permission to display 'new' visual selves to the camera. In the course of this work we amply demonstrated to ourselves that there is no single self, but many fragmented selves, each vying for conscious expression, many never acknowledged. We created a range of portraits which were the visual embodiment of our fragmented selves, which still continue to emerge every time we meet to have a photo therapy session. We have found ways of having a dialogue with ourselves about the conflicts and constraints of marriage, or of health, education, aging, class economics and oppression for us as women, and working 'against the grain' around dominant definitions of sexuality and love.

Ways in which I have used the camera therefore include taking naturalistic photographs as things happened to me and around me (what is called documentary photography); staging things specially for the camera; using old personal photographs as a starting point and re-investigating what they mean. The whole technique depends upon expecting photographs to help us to ask questions, rather than supplying answers. Using this framework for photography it is possible to transform our imaginary view of the world, whilst working towards trying to change it socially and economically.

As a newly emergent middle class woman who is involved directly with ongoing cultural and ideological struggles, rather than economic ones (though at the moment I live on an average of £50 a week, out of which I have to pay for my health care), I feel it is still most useful that my time and energy be deployed within the institutions of education and the media. I believe that I can best intervene in the place in which I find myself, not look outside (as a photographer) to 'help' others.

In future I want to work more to help open up criticism around 'amateur' practices in photography, rather than (as in the past) to criticise and problematize 'professional practice'. Much of this will now revolve around 'the body politic' - concentrating on what could constitute a more social and pleasurable (through being critical) practice within amateur photography, particularly in photography within the family, of power relationships. This is where photo therapy becomes so important, to an understanding of our social identity, gendered, classed and racially determined. Questions integral to health identity, what we feel we are capable of doing and changing in relation to our wellbeing. ♀

Next month, KIT MOUAT continues our three part series on cancer by looking in more detail at how cancer patients are controlled by the drug companies and the medical establishment. JO SPENCE will conclude the series with some questions to ask ourselves about illness, and an extensive list of resources and contacts.

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